Understanding

Prostate Cancer

Caring for people with cancer
This booklet has been written to help you to understand more about prostate cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on prostate cancer, its treatment and how it may affect you.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information that you may need.

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This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave their time and expertise to previous editions of this booklet.

Special thanks to Mr David Galvin, Consultant Urologist and Professor Ray McDermott, Consultant Medical Oncologist, whose review of Understanding Locally Advanced and Advanced Prostate Cancer has informed the current booklet.

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- European Society for Medical Oncology Guidelines 2018.

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Quick facts

**Can my cancer be treated?**

Yes all stages of prostate cancer can be treated. Your doctor will discuss with you what treatments will be of most benefit to you.

**Will I be OK?**

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, and every man’s prognosis is different. The prognosis for prostate cancer is very good for most men, but your doctor will advise you on what is likely to happen in your situation.

**What kind of treatment might I have?**

- **Active surveillance:** Monitoring your cancer with regular blood tests, biopsies and MRI scans. If these show activity in your cancer, you will be offered treatment
- **Brachytherapy (internal radiotherapy):** Tiny radioactive seeds put into your prostate to kill cancer cells
- **External beam radiotherapy:** High-energy rays to kill cancer cells
- **Surgery:** An operation to remove your prostate gland
- **Hormone therapy:** Injections or tablets to control the cancer
- **Watchful waiting:** Having no treatment until there are signs that the disease is changing

How will my cancer and treatment affect me?

Some men with prostate cancer will have side-effects and symptoms. For example, fatigue, loss of libido (sex drive), urinary incontinence (leaking urine) and erectile dysfunction (ED). Some men may have few or no symptoms.

You can read about the treatments to learn more about their side-effects. For advice on coping with side-effects, see page 61.

There are treatments to help with most side-effects, so tell your doctor. Don’t suffer in silence!

We’re here for you

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

**Ways to get in touch**

- Call our Cancer Nurseline on 1800 200 700
- Drop in to a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 86 for more about our services.
Introduction

This booklet has been written to help you to learn more about prostate cancer.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

Reading this booklet

Remember you do not need to know everything about prostate cancer straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie.

You can also visit a Daffodil Centre. See page 86 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
What is cancer?

All cancers are a disease of the body’s cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This is also called metastasis.

What is the lymphatic system?

The lymphatic system protects us from infection and disease. It is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. Lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.

What is the prostate?

The prostate is a gland found only in men. About the size of a walnut, it lies below your bladder just in front of your rectum (back passage).

Running through your prostate is a tube that carries urine through your penis. This tube is known as your urethra or water pipe. If the prostate gland is enlarged it can cause trouble passing urine because it presses on the urethra.

The prostate makes a thick white fluid that mixes with sperm (semen). It also makes a protein called prostate specific antigen (PSA), which turns semen into liquid.

PSA test

When doctors check the prostate gland, they often do a PSA test. The PSA test measures levels of the PSA protein in your blood. Raised PSA can be a sign of prostate cancer or of a less serious condition.

Email: cancernurseline@irishcancer.ie
Understanding prostate cancer

What is prostate cancer?

Prostate cancer is when the cells of your prostate gland grow in an abnormal way to form a lump (tumour). In some men prostate cancer grows slowly, while in others it grows more quickly and spreads to other parts of your body.

Early (localised) prostate cancer: This is prostate cancer found only within the prostate gland. It has not spread outside your prostate gland. With early prostate cancer there may be no symptoms. Your doctor may only suspect it after doing a PSA test (see page 9).

Locally advanced prostate cancer: If the cancer has broken through the capsule (covering) of the prostate or has spread outside the gland to nearby tissues, it is called locally advanced cancer. Places where the cancer might spread include tissues such as your seminal vesicles, lymph nodes, neck of your bladder or your back passage (rectum). The seminal vesicles are two glands that sit just behind your prostate gland and store seminal fluid.

Some treatments for locally advanced prostate cancer hope to cure it, while others aim to control the disease or stop it from growing.

Metastatic (advanced) prostate cancer: This is when prostate cancer cells have spread and are affecting other parts of your body, away from the prostate gland. For example, your bones.

If you want information about metastatic prostate cancer, please read our booklet Understanding advanced (metastatic) prostate cancer. It’s available free from Daffodil Centres or by calling our Cancer Nurseline. You can also download it from our website www.cancer.ie

How common is prostate cancer?

In Ireland, prostate cancer is the second most common cancer in men, after skin cancer. Each year over 3,500 men are diagnosed with prostate cancer here. This means that 1 in 8 men will be diagnosed with prostate cancer during their lifetime. Although there are many men with this disease, most men do not die from it.

What increases my risk of prostate cancer?

The exact cause of prostate cancer is unknown. But there are certain things called risk factors that can affect your chances of getting the disease.

Having a risk factor doesn’t mean you will definitely get cancer. And sometimes people without any known risk factors develop cancer.

Some things that can increase your risk of prostate cancer are:

- **Age:** The risk of prostate cancer increases with age. It usually affects men over 50 and is rare in men under 50. Near 2 in every 3 prostate cancers are diagnosed in men over 65.
- **Family history:** If you have a brother or father with the disease, your risk is higher. The risk is also higher if your relative developed prostate cancer at a younger age or if you have more than one relative with the disease.
- **Race:** Afro-Caribbean men are at a higher risk of developing prostate cancer.

Remember prostate cancer is not infectious and cannot be passed on to other people.

To sum up

- Prostate cancer is common, especially in older men.
- Early prostate cancer is cancer that is found within your prostate gland and has not spread elsewhere in your body.
- Locally advanced prostate cancer is prostate cancer that has broken through the capsule (covering) of the prostate or has spread outside the gland to nearby tissues.
Diagnosis and tests

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What tests will I have?

After being diagnosed with prostate cancer, your doctor may want to do more tests to find out more about your cancer and your general health. Whether you need any tests or not depends on the results of your PSA, Gleason score (see page 18) and how your prostate gland feels to touch. Your doctor will let you know which tests you need to have, if any. Some tests can be used to see how you are responding to treatment.

Tests you may have include:

**Biopsy:** Taking samples of prostate cells with a needle. These are examined under a microscope to see how abnormal the cells are.

**CT scan (CAT scan):** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. You might be asked not to eat (fast) for a few hours before the scan. You may also be given an injection or a special drink to help show up parts of your body on the scan.

Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It does not hurt and takes between 10 and 30 minutes. This test is usually done as an outpatient, so you should not need to stay in hospital.

**MRI scan:** This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. You might get an injection before the scan to show up certain parts of your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic. If you are anxious, contact...
Understanding prostate cancer

You cannot wear metal jewellery. The scan does not hurt but it can be noisy. You will be given earplugs to wear. Usually you can go home after the scan.

**Bone scan:** Bone scans are very sensitive and can detect any cancer cells in the bone before they show up on an X-ray. For this test a very small amount of mildly radioactive substance is injected into a vein, usually in your arm. After the injection you must wait for up to 3 hours before the scan can be taken. You may want to take a book or magazine with you or a friend to keep you company. A scan is taken of all the bones in your body.

Because abnormal bone absorbs more of the radioactive substance than normal bone, it can show up on the scan. The level of radioactivity used in these scans is very low and safe. It disappears from the body within a few hours. But it is best to avoid contact with pregnant women and very close contact with babies or young children for 24 hours (such as holding them or letting them sit on your lap).

**X-rays:** You may need bone X-rays if the bone scan shows doubtful areas in certain bones. These X-rays will help to confirm whether you have benign (non-cancerous) or malignant (cancerous) bone disease.

**Waiting for test results**

It usually takes about a week for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

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**Staging prostate cancer**

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. Staging means finding out the size of the cancer and if it has spread to other parts of your body.

**How is prostate cancer staged?**

There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).

**What are the stages of prostate cancer?**

**Tumour – How big is the tumour?**

- **T1** The tumour is within your prostate gland. It is too small to be felt during a rectal exam.
- **T2** The tumour is still within your prostate gland. It is large enough to be felt during a rectal exam.
- **T3** The tumour can be felt throughout your prostate, and may have broken through the outer layer of the prostate.
- **T4** The tumour has spread to organs outside your prostate gland.

**Node (N) – Are the lymph nodes affected or not?**

- **N** Cancer is present in the lymph nodes
- **N0** No cancer in the lymph nodes
- **N1** Cancer has spread to 1 or more of the lymph nodes

If you have been diagnosed with early prostate cancer you will see **N0** as the cancer has not spread out of the prostate.

**Metastasis (M) – has it spread outside the prostate?**

- **M** The cancer has spread to lymph nodes and/or other organs, commonly bones.
- **M0** The cancer has not spread

If you have been diagnosed with early prostate cancer you will see **M0**, as the cancer has not spread outside the prostate.
Understanding prostate cancer

Risk groups
Your doctor may use your Gleason score, the stage of your cancer and your PSA level to describe your cancer as low, intermediate, high or very high risk. These risk groups reflect the level of risk to your future health from this prostate cancer.

Knowing the grade of your cancer can help your doctor to plan the best treatment for you.

Prognostic grade groups
Some doctors describe prostate cancer as a prognostic grade group, using numbers 1 to 5.

Grades go from grade 1, which has the best outlook, up to grade 5, which describes cancers which grow more quickly.

The prognostic grade group is worked out from the Gleason score by the pathologist.

Asking about your prognosis
Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

It is not always easy for doctors to answer a question about life expectancy, as the answer is based on a ‘typical’ experience. Experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

Grading prostate cancer
Grading helps your doctor to predict how the cancer will behave.

How is prostate cancer graded?
A doctor called a pathologist will look at samples of your prostate cells under a microscope. The pathologist will give the cells a grade. The grade is a number from 3 to 5 which describes how normal or abnormal the cells look. A lower number means the cells look more like normal cells. A higher number means they look less like normal cells.

What is the Gleason score?
The Gleason score will be described using a number from 6 to 10. The pathologist will add the two most common grades together to make the Gleason score. So if the most common grade in the sample is 3, and the second most common grade in the sample is 4, then your Gleason score will be 7 (3 + 4). However, if only one grade is found, then this grade is added to itself. So if all the sample is only grade 3, then the Gleason score will be 6 (3 + 3).

Lower grades are slower growing.
Higher grades are faster growing.

If you have any questions about the stage or grade of your cancer, or you find it hard to understand, tell your doctor or nurse. You can also ask one of our cancer nurses. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.
If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn’t understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

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### Treating prostate cancer

- **How is prostate cancer treated?**
- **Deciding on treatment**
- **Decision aid tool**
- **Who will be involved in my care?**
How is prostate cancer treated?

Your prostate cancer can be treated in a number of ways. You may be given a choice of treatments. Sometimes the treatment is to get rid of the prostate cancer completely. If this is not considered likely, the treatment aims to control the cancer or slow its growth.

Which treatment options are suitable for you depends on:
- The stage of your cancer, for example, if it has spread outside the prostate gland
- The grade of your cancer (see page 18)
- Your PSA level
- The size of your prostate gland
- If you have urinary symptoms or not
- Your general health

Types of treatment

Active surveillance: Active surveillance means you don’t start treatment straight away. Instead you have regular tests like blood tests, MRIs and biopsies to spot any changes or activity in your cancer. This way you can avoid treatment side-effects for as long as possible and still start treatment to cure your cancer as soon as you need it.

Active surveillance can carry on for many years if your cancer shows no signs of changing. See page 32 for more details. This is a treatment option for low-risk prostate cancer, which can be very slow growing and often does not cause symptoms or problems. Active surveillance is not suitable for locally advanced prostate cancer.

Brachytherapy (internal radiotherapy): This involves putting radioactive seeds into your prostate to kill cancer cells (p35).

External beam radiotherapy: External beam radiotherapy uses X-rays to kill cancer cells. You may have radiotherapy together with hormone therapy (p43).

Surgery: The operation to remove your entire prostate gland is called a radical prostatectomy. There are several ways of doing it.

For example, traditional open surgery, keyhole surgery, and robotic keyhole surgery. See page 50 for more details.

If prostate cancer is found outside your prostate gland during the operation, you may need to have radiotherapy after the surgery as well. Your doctor and specialist nurse will explain this to you in more detail.

Hormone therapy: Prostate cancer depends, in part, on the male hormone testosterone to grow and spread. By reducing the amount of testosterone in your body, the growth of cancer cells can be slowed down or stopped. In certain circumstances hormone therapy is used together with radiotherapy for early or locally advanced prostate cancer. See page 48 for more details on hormone therapy.

Watchful waiting: Prostate cancer often grows slowly and does not cause symptoms. For some men with prostate cancer who have other health issues this may be a reasonable option. Watchful waiting is different from active surveillance. It involves PSA testing but no repeat biopsies. See page 59 for more information.
Deciding on treatment

**Multidisciplinary team:** A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a surgeon (urologist), specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

**Treatment options:** Your doctor and nurse will explain your treatment options to you. Your doctor will try to tell you if one treatment is better than another at getting rid of your cancer, but often the treatment options are all thought to be equally good at treating early prostate cancer.

Don’t be afraid to ask as many questions as you need to. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

**Time to think:** You may feel under pressure to make a decision. It may feel as if everything is happening too fast. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

**Second opinion:** You might also find it reassuring to have another medical opinion to help you make a decision about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

**Making a treatment decision**
Many men may find it stressful having to choose between treatment options, and worry that they will choose the wrong one.

It’s important to take enough time to think through the pros and cons of each treatment and then decide which suits you best.

You can ask to talk to a urologist and a radiation oncologist before you make up your mind. You may also find it helpful fill in the decision aid tool on page 28, once you have read about the different treatments.

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**Why am I being asked to make a decision?**

Very often there are several different treatments for prostate cancer which are all equally good. There is no right or wrong treatment, so it’s up to you to decide which treatment suits you and your lifestyle the best.

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**Hints & Tips – making a decision**

Things to think about when deciding:
- How do I feel about monitoring my prostate cancer?
- How long does the treatment take?
- How do I feel about staying in hospital?
- What is the recovery period for each treatment?
- What are the side-effects of each treatment?
- How will those side-effects change my daily life?
- How many times will I need to visit the hospital?
- How far will I have to travel to the hospital for treatment?
- How long will I need to take off work?

It may be helpful to:
- Know your results and write down your PSA and Gleason score and the stage of your cancer
- List each of the options that are available to you
- Write down what you like and don’t like about each option
- Ask yourself how important these points are to you (individually) and to your family. The decision tool on page 28 can help you.
- Write down what is the most important goal for your treatment
- Talk to other men who have received these treatments and find out about their experiences and how they managed any side-effects. The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a prostate cancer diagnosis. For more information contact our Cancer Nurseline on 1800 200 700.
Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment: Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:
- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Individual treatment: You may notice that other people with prostate cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage or grade as yours. Everyone’s treatment needs will be different. Don’t be afraid to ask your doctor about your treatment.

Have some questions ready about the treatment and how it may affect you physically, emotionally, socially.

Keeping track of information

You may like to fill in these tables with information about your cancer and treatment. Or if you prefer, ask your doctor or nurse to fill them in for you. Ask them to explain the information again if you are unsure.

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<td>Clinical stage at diagnosis</td>
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<td>Number of biopsy samples taken</td>
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<td>Number of biopsy samples with cancer</td>
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<td>Gleason score</td>
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Tick all the treatment options suitable for you:

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<th>Treatment options suitable for me</th>
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<td>Active surveillance</td>
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<td>Brachytherapy</td>
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<td>External beam radiotherapy</td>
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<td>Surgery ■ Laparoscopic prostatectomy (keyhole surgery)</td>
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<td>■ Open surgery</td>
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<td>■ Robot-assisted laparoscopic prostatectomy (robotic surgery)</td>
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<td>Watchful waiting</td>
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<tr>
<td>Hormone therapy</td>
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### Decision aid tool

To help you make a decision about your prostate cancer treatment, fill in this chart together with your nurse or doctor. For each of the treatment options suitable for you, list the advantages and disadvantages. Rank each advantage and disadvantage between 0 and 4. The higher the number, the more this matters to you.

<table>
<thead>
<tr>
<th>Treatment options suitable for me</th>
<th>Advantages</th>
<th>Score</th>
<th>Disadvantages</th>
<th>Score</th>
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0  This does not matter at all to me.
1  This matters a little to me.
2  This does not matter either way to me.
3  This matters to me.
4  This matters a lot to me.

### Who will be involved in my care?

Usually a team of healthcare professionals will be involved in your treatment and care.

**Surgeon / urologist** A doctor who specialises in surgery and who can remove a tumour from your body.

**Radiation oncologist** A doctor who specialises in treating cancer patients using radiotherapy.

**Radiation therapist** A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

**Oncology liaison nurse / clinical nurse specialist** A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

**Medical social worker** A person trained to help you and your family with all your social issues and practical needs.

They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.

**GP (family doctor)** You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

**Physiotherapist** A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

**Dietitian** An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms.

**Psycho-oncology team** These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

**Psychologist** A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
Counsellor A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Community health services These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Waiting for treatment to start
It may be a few weeks before active treatment starts. You may be worried that the cancer will spread if you wait. But with most prostate cancer there is no need to rush treatment.

Having some time can give you the chance to talk through your feelings and try to come to terms with your diagnosis. If you want to talk to a cancer nurse, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The nurses can also put you in touch with a man who has had treatment for prostate cancer, if you think this would be helpful.

You could also try to make healthy changes like stopping smoking or trying to lose any extra weight. It can be hard to make changes during an anxious time like this, but it may help your recovery. For example, leaking urine is common after surgery. Extra weight around your tummy or a cough from smoking can make leaking worse.

You could also start pelvic floor exercises to strengthen muscles in the area. This might help with leaking urine and erection problems after treatment. See page 65.

Speak to your doctor for advice and support on how to make these changes.
Active surveillance

Active surveillance is a way to delay unnecessary treatment and avoid treatment side-effects. Slow-growing, low-risk prostate cancer may not grow or change for many years. You may never need treatment for your prostate cancer, or you may be able to hold off having treatment for a number of years.

Treatments for prostate cancer often cause side-effects that can affect your quality of life, so you could choose to have active surveillance rather than treatment. If your cancer starts to change or grow, then you can start treatment.

Who can have active surveillance?

If you have prostate cancer that is seen as low risk (see page 19), you may be suitable for active surveillance. If you have a medium-risk prostate cancer, you may be suitable too. It will also depend on your age, the amount of low-risk cancer in your biopsy and your general health.

If you have high-risk cancer you will not be suitable for active surveillance, as your doctor will want to start active treatment to get the cancer under control.

What does active surveillance involve?

Active surveillance involves regular tests to check (monitor) your cancer. These tests aim to find any changes in the cancer. If any changes are noticed, your doctor will talk to you about the need for treatment. The tests usually include:

- **PSA blood tests** every few months at the start, and then every 6 months after a couple of years
- **Regular digital rectal exam** (where the doctor examines your prostate gland through your rectum (back passage)).
- **Prostate biopsies** (taking samples of prostate tissue) You may require one or more biopsies while on active surveillance.
- **An MRI scan** when you have started active surveillance. You may have several other MRIs while you’re on active surveillance.
Brachytherapy

Brachytherapy is a type of radiotherapy. With brachytherapy the radiation source is placed inside your body. The radiation comes from tiny radioactive pellets or seeds. The seeds release radiation slowly over a number of months. The radiation destroys prostate cancer cells. The seeds are not removed and the radiation fades away over time. It is a safe therapy.

The aim of brachytherapy is to fully cure your prostate cancer.

The doctor who specialises in giving radiotherapy is called a radiation oncologist. The treatment is usually used on its own. But if there is a higher chance of the cancer spreading, it can be used together with external beam radiotherapy (see page 43) and hormone therapy (see page 48).

Who is suitable for brachytherapy?

Not all men are suitable for brachytherapy. It will depend on the stage and grade of your prostate cancer and the size of your prostate gland.

You may not be suitable if you have trouble passing urine, have a very large prostate gland or have recently had surgery to your prostate gland. Your doctor will let you know if you are suitable for brachytherapy or not.

If you have a larger prostate gland, you may be given hormone therapy to shrink it before brachytherapy. If you have higher-risk prostate cancer, you may receive brachytherapy along with another treatment. For example, you may need some doses of external beam radiotherapy or hormone therapy as well.

HDR brachytherapy

In a small number of situations you may be offered a different type of brachytherapy called HDR brachytherapy.

HDR brachytherapy uses a high dose of radiation. Instead of using permanent seeds, a temporary source of radiation is inserted into the prostate gland for a few minutes.
HDR brachytherapy is usually combined with external beam radiation and/or hormonal therapy, but your doctor will discuss your individual treatment plan with you.

What happens before brachytherapy treatment can be given?

An ultrasound scan of your prostate is done first. This happens some weeks before the seeds are put in. The scan lasts about 15 minutes. The scan can take pictures of your prostate. The probe that produces the pictures is put into your back passage. The pictures will show the exact size and shape of your prostate so the doctor knows how many seeds need to be used and where they should be placed. Your nurse will let you know if your bowels need to be empty for the test.

How are the seeds put in?

The day before the seeds are put in (implanted), you may be asked to follow a special diet and have an enema to clear your bowels. An enema is a fluid solution gently put into your bowel through your back passage. The hospital staff will explain this to you and let you know about any medication to avoid beforehand as well.

You will be taken to an operating theatre to have the seeds put in under a general or spinal anaesthetic. An ultrasound probe is first put in your back passage to show up your prostate. Then around 60 to 120 radioactive seeds are put into your prostate through the skin between your scrotum and anus using a fine needle. You will not be cut. It takes about 90 minutes to put in all the seeds.

After brachytherapy

You prostate may get swollen after brachytherapy, so a tube (catheter) will be put into your bladder during the operation. The tube will drain any urine. It may be left in for a couple of hours or overnight.

It is common to feel mild soreness and some bruising between your legs for a few days after the seeds have been put in. Your doctor can prescribe mild painkillers to relieve this. You may see some blood in your urine afterwards, but most bleeding usually goes within 48 hours. If it goes on beyond that, let your doctor know. To help prevent blood clots and flush out your bladder, drink plenty of fluids (about 1½ to 2 litres a day).

You will be given antibiotics to prevent an infection. You may also be given a prescription for painkillers and alpha blockers. Alpha blockers are tablets to help relax your bladder and make it easier to pass urine. Usually you will be able to go home the same day once you have recovered from the anaesthetic and can pass urine normally.

You will be given a follow-up appointment 4 to 6 weeks after your brachytherapy. This is a time to check the positioning of the seeds with a CT scan and for you to talk about any side-effects that may be bothering you. For more about follow-up, see page 70.

Hints & Tips – after the seeds are put in

- Do not drive for 24 hours after having a general anaesthetic.
- Take it easy and avoid heavy lifting and straining for 2 or 3 days.
- It is safe to bathe or shower any time after the seeds are put in.
- Return gradually to your regular diet.
- Avoid foods that may irritate your bowel and avoid getting constipated.
How safe is the radiation?
The radiation is released into your prostate gland over the first few months. This radiation is then absorbed by your prostate. After about 12 months, the seeds are no longer active and can stay in your prostate without doing any harm. The exact amount of time it takes for the radiation to be released will depend on the type of radioactive substance used. For this reason it is important to follow the guidelines given to you by your hospital.

It is safe for you to be around other people and pets during this time. The radiation released by the seeds targets the prostate gland only. But as a precaution it is best to avoid close physical contact (less than an arm’s length) with small children or pregnant women for the first 2 months after treatment. This means not allowing children to sit on your lap for more than a few minutes each day. You should also avoid sitting close to a pregnant woman for more than 30 minutes.

How long do the seeds stay in my body?
The seeds remain permanently in your prostate gland. There’s a slight chance that a seed could be passed out in your semen or urine, although this is rare. If you do pass a seed, tell the radiotherapy unit. Do not handle the seed with your fingers and flush it down the toilet.

Medical alert card
Because you will have radioactivity in your body for a time after brachytherapy, the radiotherapy unit may give you a medical alert card detailing the treatment you have had. This is to alert other medical professionals if you have a medical emergency. It’s important to carry this with you all the time, for the amount of time recommended by the unit.

This card is also necessary for airline travel, as some of the security sensors may be triggered by the weak radiation emitted from the seeds. If you need to go into hospital and have an operation for another reason during the first year after treatment, speak to your brachytherapy unit about the risk of exposure from radiation.

What about sex after brachytherapy?
It is safe for you and your partner to sleep in the same bed (if your partner is not pregnant). You can talk to your doctor or nurse about when you can start having sex again after brachytherapy.

You may not feel like having sex in the first few weeks after treatment. This can be due to tiredness or side-effects like pain or swelling around the area of the prostate. These symptoms normally ease with time.

There is a small risk that a seed may come out in your semen when you are having sex. You should use a condom to catch the semen the first 4-5 times you have sex. Don’t worry if your semen is black or brown in colour. This is normal and due to bleeding when the seeds are put in.

Hints & Tips – brachytherapy
- Wait 2 weeks after treatment before having sex.
- If a seed comes out, flush it down the toilet.
- If you need a bowel or prostate test after brachytherapy, speak to your radiation oncologist first.
- You may be given a medical alert card, which you should carry at all times. In the event of an emergency, this will let medical staff know that you have had brachytherapy.

What are the side-effects?
It may take a few days before you experience any side-effects. Usually they are at their worst a few weeks after the seeds have been put in. You may get some or all of the side-effects. Each man experiences them differently, so it is hard to predict exactly how you will feel. The most common side-effects include:
- Urinary problems
- Erectile dysfunction
- Bowel problems
- Fatigue (tiredness)
- Infertility
**Urinary problems:** The radiation can irritate and inflame the tube through which you pass urine (urethra) and your bladder. This can cause symptoms such as a burning sensation when you pass urine, needing to pass urine more often, having a slow stream, finding it harder to start passing urine, and needing to go more quickly than you used to. If you cannot pass urine afterwards, this is called urinary retention. This doesn’t happen very often but if it does, you will need to have a tube (catheter) put in for a time. Urinary side-effects get worse in the first few weeks after treatment, when the radiation is strongest. You may need to go to the toilet very often, day and night. This can interfere with your normal daily activities for a while. Urinary side-effects usually improve over time as the seeds lose some of their radiation.

If you have urinary symptoms before brachytherapy, you are at higher risk of having problems passing urine after the treatment. Leaking urine (incontinence) is rare after brachytherapy. If you have had surgery to your prostate gland before brachytherapy, you will have a higher risk of incontinence.

There is more information on urinary symptoms and how to manage them on page 63. Or look at our website www.cancer.ie

**Erectile dysfunction:** Brachytherapy can cause damage to the nerves and blood vessels near your prostate gland. This means that you might not be able to get normal erections after the treatment. This is called erectile dysfunction (ED) or impotence. You may not notice it until years after your treatment. It may also become a long-term problem or be permanent. 2 years after brachytherapy, 2 out of 10 men have erectile dysfunction. 3 years after brachytherapy, 4 out of 10 men may have it. Your risk of erectile dysfunction will increase if you have had erection problems before your treatment. If you have hormone therapy and external beam radiotherapy together with your brachytherapy, you are at a higher risk of erectile dysfunction than men who have brachytherapy alone.

You may find this side-effect of treatment very hard to deal with. It can affect your relationship with your partner and your sex life.

Do not feel embarrassed to talk to your doctor or nurse about this problem. There are practical ways and several treatments available to help overcome it. See pages 66–70 for more information. You can also call Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

**Bowel problems:** You may get inflammation of your bowel after brachytherapy. This may cause some bleeding or a change in your bowel habit, such as needing to go to the toilet more often. Avoid foods that may irritate your bowel and avoid getting constipated. Bowel problems can appear straight away or up to 2 to 3 years after your treatment. If this happens, talk to your doctor. There may be treatments that can help. It’s important that any doctor who treats you for bowel problems after brachytherapy is aware that you have had brachytherapy. If you are unsure, contact the hospital where you had treatment for advice.

**Fatigue (tiredness):** You may experience tiredness from the anaesthetic or from getting up a lot at night to pass urine. It usually takes a few months for this to improve after treatment. See page 62 for more on coping with fatigue.

**Infertility:** Brachytherapy for prostate cancer may affect your fertility. This means you might not be able to father a child in the future. If this is important to you, talk to your doctor about this effect before your treatment. See page 70 for more about fertility. Remember it is not safe to assume you are sterile after radiotherapy, so you will need to use contraception.

Our booklet *Understanding Radiotherapy* has more information on brachytherapy. For a free copy, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie

**Advantages of brachytherapy**
- Treatment time is short: 1-2 days.
- You can return to your normal routine quite quickly.
- Compared to external radiotherapy, brachytherapy may have fewer immediate side-effects and cause less damage to surrounding tissues like the back passage, urethra and bladder.
External beam radiotherapy

External radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

The treatment is suitable if your prostate cancer is found only within your prostate gland or has spread just outside it. The aim of radiotherapy is to fully get rid of your prostate cancer.

Radiotherapy and hormone therapy (see page 48) are often used together to treat locally advanced prostate cancer. This helps to make the radiotherapy work better at controlling your prostate cancer. Radiotherapy is suitable for most men, although it may not be the best option if you have urinary symptoms.

Planning your treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to nearby cells. An important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken, but this is to plan your treatment only. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. You might also have gold markers called fiducials put into your prostate to make sure the radiotherapy targets the right area. These are put into your prostate gland under anaesthetic before the treatment starts.

Special diet and fluids: Your prostate gland must be in the same position every time you have your treatment. The position of your prostate can be affected by how full your bladder or bowel is. To make sure your prostate is in the same position each time, you may have to follow a special diet, drink some water just before your treatment, or have an enema. An enema is a fluid solution gently inserted into your bowel through your back passage, which causes you to clear your bowels.

Disadvantages of brachytherapy

- It can cause urinary, erection and bowel problems.
- You may have some temporary discomfort after the procedure.
- You will need to have a general anaesthetic.
- You may not be able to have prostate surgery in the future, due to the effects of the radiotherapy.

To sum up

- Brachytherapy is a way of giving radiation directly into your prostate gland.
- The radiation comes from small radioactive seeds put into your prostate under general anaesthetic.
- Having brachytherapy depends on the stage and grade of your prostate cancer and the size of your prostate gland.
- The radiation is released slowly over a number of months.
- After several months, the seeds are no longer active and stay in your prostate without doing any harm.
- The most common side-effects include urinary problems, erectile dysfunction, bowel problems, fatigue and infertility.

Spend time gathering your own research, talk to a lot of different people and make the decision that is right for you.
Getting your radiotherapy treatment
During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles or in an arc. The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day, with a break at weekends. Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. The centre may be some distance from the hospital where you had surgery or chemotherapy.

How much radiotherapy do I need?
The course can be several treatments over a number of days or weeks (usually 7 to 9 weeks). How much treatment you receive will depend on the extent and exact location of your cancer. External radiotherapy does not make you radioactive. It is completely safe for you to mix with family and friends, including pregnant women and children.

What are the side-effects of radiotherapy?
Most of the side-effects that happen affect the part of your body being treated. How severe any side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks.

Short-term (acute) side-effects

Urinary problems: Burning sensation when passing urine, needing to go to the toilet more often or blood in your urine. See page 63 for tips to manage urinary problems.

Bowel problems: Diarrhoea (loose, semi-solid bowel movements) or constipation (not having a bowel movement often enough), cramping pain in your tummy, passing more wind or mucus, needing to get to the toilet more quickly or mild bleeding when you go to the toilet.

Drink lots of fluids if you have diarrhoea. You may also be advised to avoid high-fibre foods such as raw fruit and vegetables, as they may make things worse. The hospital team will help you find ways to manage your bowel symptoms during your treatment. These symptoms usually start to settle down a short time after your treatment has stopped.

Fatigue: Feeling very tired, even after rest. See page 62 for more about fatigue.

Late, long-term or permanent side-effects
Late side-effects may develop some time after treatment. Some side-effects last for a long time or may even be permanent, but it is rare to have long term problems.

Erectile dysfunction: Radiotherapy to your prostate can damage the nerves and blood vessels that control erections. This can make it difficult for you to get and keep an erection, especially if you are taking hormone therapy as well. This is called erectile dysfunction or impotence. It can take up to 2 years for this side-effect to be noticed.

Erectile dysfunction occurs in about 4 out of 10 men. If you have had problems with erectile dysfunction before radiotherapy, you are more likely to have problems with erections afterwards. Having erectile problems will also depend on your age and general health.

There is some evidence that taking tablets or using vacuum therapy for erectile dysfunction soon after radiotherapy may reduce your risk of erectile problems. See pages 66-67 for more information.

You may not be interested in sex at first. But taking the tablets or using a vacuum pump at an early stage may improve your chances of getting erections when you are ready to think about sex again. Do discuss this with your doctor, nurse or GP.

There are several treatments available for erectile dysfunction. For more information see page 66 or visit our website. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre, or email the nurses at cancernurseline@irishcancer.ie
Urinary problems: A very small number of men find their bladder is permanently affected by radiotherapy. They may develop symptoms like needing to go to the toilet more often or pain when passing urine months or years after radiotherapy. Some men’s urethra (water pipe) narrows, which can make it difficult to pass urine. Narrowing of the urethra needs to be treated with surgery.

A few men have blood in their urine after radiation therapy, sometimes many months or years after treatment. This is because the blood vessels in your bladder can become more fragile after radiotherapy. If you notice any bleeding, tell your doctor so that tests can be done to check the cause and decide if any treatment is needed.

Rarely, radiotherapy can cause urgency to pass urine, resulting in leakage of urine. But this is unlikely unless you have had prostate surgery as well. If this happens, discuss it with your doctor or nurse.

Bowel problems: In some cases bowel problems might carry on. Or they might develop years after treatment and you find that your bowel habits change permanently. Bowel motions may be more urgent and frequent after radiotherapy. Tell your doctor about any bowel problems that you have, as there are treatments that can help.

The blood vessels in your bowel can also become more fragile after radiotherapy. This can cause blood to appear in your bowel motions. Other bowel problems are common in older men, so symptoms may be due to something else. You may need to have a few tests to find out the cause of your symptoms. If you have ongoing problems with diarrhoea or rectal bleeding, do tell your doctor or nurse.

‘Dry’ orgasm: After radiotherapy, some men find that an orgasm has less semen than usual or they have a ‘dry’ orgasm, where no semen is ejaculated. Dry orgasm means you won’t be able to father a child, as there is no semen. See below for more about infertility.

Infertility: Radiotherapy for prostate cancer may cause infertility. If this happens, it means you cannot father a child in the future.

If this is important to you, talk to your doctor about this effect before your treatment to see if there are any options open to you, such as sperm-banking before treatment. See page 70 for more about fertility. It is not safe to assume you are sterile after radiotherapy, so you will need to use contraception.

If you feel unwell or have any other side-effects or symptom, tell your doctor, nurse or radiation therapist. For more information on the different types of radiotherapy and the side-effects of radiotherapy or a copy of the booklet Understanding Radiotherapy, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Advantages of external beam radiotherapy
- You don’t need a general anaesthetic and you don’t need to stay overnight in hospital.
- You may be able to work and carry on normal activities during the treatment.
- You are not radioactive during or after the treatment so you can be in close contact with others.
- Each treatment is relatively short. It usually takes about 15 minutes, although you may be in the radiotherapy department for up to an hour.

Disadvantages of external beam radiotherapy
- It may be difficult if you have far to travel to the radiotherapy unit.
- It may take some time to see how effective the radiotherapy has been.
- You may not be able to have prostate surgery in the future due to the effects of the radiotherapy.
- You might experience side-effects such as bowel or urinary problems, erectile dysfunction and fatigue. Some of these side-effects may develop or get worse over the longer term.
- You may become infertile.
- Treatment may very slightly increase the risk of getting a second cancer.
To sum up
- With external beam radiotherapy a beam of radiation is aimed at your prostate gland from a machine called a linear accelerator.
- The treatment is suitable if your prostate cancer is found only within your prostate gland or has spread just outside it.
- You will need to go to hospital for treatment planning before the radiotherapy can be given.
- Short-term side-effects of radiotherapy include passing urine more often, diarrhoea, discomfort at back passage and fatigue.
- Long-term side-effects are rare and include erectile dysfunction, urinary problems, bowel problems and infertility.

Radiotherapy and hormone therapy
For some types of prostate cancer, giving hormone therapy together with radiotherapy can make the treatment more effective.

Hormone therapy can be given for different lengths of time. Typically it starts some months before radiotherapy and continues during and after treatment for a period of months or years depending on your individual circumstances. Ask your radiation oncologist for how long you will need to take the treatment.

Hormone therapy
Hormones in your body control how normal cells grow and work. Prostate cancer depends in part on the male hormone testosterone to grow and spread. By reducing the amount of testosterone in your body, the growth of cancer cells can be slowed down or stopped. Hormone therapy can be used to reduce the amount of testosterone made by your testicles. These drugs can be given as tablets or injections.

Side-effects of hormone therapy
Most side-effects of hormone therapy happen because reducing testosterone changes the balance of hormones in your body. Possible side-effects include:

- **Hot flushes**: These affect more than half the men who get hormone therapy. Some men find them difficult to cope with.
- **Breast swelling and tenderness**: This can vary from mild tenderness, with or without swelling, to more noticeable tissue growth around the breast area.
- **Osteoporosis or bone thinning**: Bones can become more brittle and more likely to break (fracture).
- **Weight gain and muscle loss**: You may gain weight, particularly around your waist. Your muscle tone and strength can also be reduced.
- **Fatigue**: Extreme tiredness is a common side-effect. Fatigue can affect your energy, mood and concentration. See page 62 for more.
- **Mood or concentration problems**: Less testosterone can lead to mood changes, poor concentration or memory problems, anxiety and sometimes depression.

See our website www.cancer.ie for more on hormone therapy and advice on managing side-effects like hot flushes and bone thinning.

Hormone therapy and sex
Hormone therapy can have a big impact on your sex life. Because hormone therapy reduces the male sex hormone testosterone, it can affect your interest in sex (libido) and your ability to get an erection. Libido can come back once you stop taking hormone therapy, although it can take many months. See page 66 for more about sexual side-effects.

> Staff are friendly and will inform and support you.
Understanding prostate cancer

**Surgery**

The aim of surgery is to remove the prostate cancer. The operation is called a radical prostatectomy. It involves removing your prostate gland and the seminal vesicles, which are glands near your prostate that produce some of the fluid in semen. Sometimes lymph nodes and nearby tissues may be removed as well. The surgeon who removes your prostate gland is called a urologist.

**Who is suitable for a radical prostatectomy?**

Surgery is suitable if the cancer is found only in your prostate gland and you are fit and healthy. Surgery may be more risky if you have health problems such as heart disease or if you are very overweight. In this case, your surgeon will advise you to have one of the other treatments for early prostate cancer.

Surgery to remove your prostate gland is a big operation. It has risks such as bleeding, blood clots and infection. The average stay in hospital is 5–7 days but can be shorter or longer. You will need some time to recover at home afterwards as well. Once the prostate gland is removed, it will be examined under a microscope in the laboratory. The doctor will check the grade of the cancer cells again (See page 18). They will also check that the edges of the prostate are clear of cancer, called 'checking the margins'.

**Negative margins:** No cancer cells

**Positive margins:** Cancer cells found at the edge of the prostate.

These tests are used to predict your response to the treatment along with PSA checks. Your PSA level should drop within weeks of surgery.

**What are the types of surgery?**

Surgery to remove your prostate gland can be done in a number of ways. Not all of the treatments are available in all hospitals in Ireland, so discuss your preference with your surgeon.

**Robot-assisted laparoscopic prostatectomy (robotic surgery):** This operation is a type of keyhole surgery but with the use of a computer and robotic arms to help to remove your prostate.

**Open prostatectomy:** Open surgery means removing your prostate through a cut in the wall of your abdomen between your belly button and pubic bone or through a cut between your scrotum and back passage.

**Laparoscopic prostatectomy:** With keyhole surgery, small cuts are made in your abdomen so that special instruments can remove your prostate.

You will be in hospital for a much shorter time with robotic or keyhole surgery than with open surgery. There is also a lower risk of needing a blood transfusion or getting a wound infection. The long-term side-effects of this type of operation are the same as for open surgery. Specially trained surgeons are needed to do these types of surgery.

**Nerve-sparing surgery**

Sometimes having to remove all the cancer cells means that the two bundles of nerves attached to the prostate will be damaged. These nerves control erections. If the nerves are damaged during the operation it will cause problems with getting an erection in the future.

If the cancer has spread too close to the nerves, your surgeon may need to remove one or both bundles of nerves. In some cases, it is possible to spare nerves on one side of your prostate. This is called a nerve-sparing prostatectomy. It gives you a better chance of regaining erections than if you had both of the nerves removed, but not as good as if you had both bundles of nerves spared. Ask your surgeon if nerve-sparing surgery is possible for you or not. Very often surgeons can’t tell until the operation itself if they can do a nerve-sparing operation or not.

**Having the surgery**

**Tests:** To make sure you are fit for surgery, you will need some tests. For example, blood tests, heart tracing (ECG), chest X-ray and a physical exam. An anaesthetist may also examine you to make sure you are fit for surgery. He or she will also discuss pain relief with you.
Risks: Prostate surgery has the same risks as any big operation. These include bleeding and the need for a blood transfusion, chest infection, blood clots and wound infection. Your doctor will discuss these risks and the side-effects of surgery before you sign a consent form.

Exercises: Before surgery, a physiotherapist or nurse might show you how to do simple exercises to strengthen the muscles that help control your urinary flow. These are known as pelvic floor exercises (see page 65). You may also be shown how to do deep breathing and leg exercises to prevent a chest infection or blood clot afterwards. You may be given some elastic stockings to wear and an injection of an anti-clotting drug like enoxaparin (Clexane®) to reduce the chance of blood clots forming in your legs.

Fasting: You cannot eat or drink anything for a few hours before surgery. The operation takes between 2 and 4 hours but you will also spend some time in the recovery room while recovering from the anaesthetic.

After surgery
When you wake up, you may have drips and tubes attached to your body. For example:
- A drip into your arm or neck to give you fluids until you can drink again
- A flexible tube (catheter) to drain urine into a bag
- A tube (drain) near your wound to drain away any fluid

If you have open surgery you may have a tube into your back which gives you drugs to relieve any pain.

When you begin to drink again, the drip will be removed. All other tubes and drains will be taken out over the first couple of days, except for the urinary catheter. You will go home with this tube. It will be left in for about 1 to 3 weeks. See page 54 for more about catheters.

Pain: With open surgery you will probably have a special pump for relieving pain. This gives you a constant supply of painkillers, either into your spine (epidural) or into a vein in your arm. Your nurse will show you how to use it.

Often the pump is a patient-controlled pump. This means there is a button on the pump that you can press to release the medication when you need it. Once the pump is stopped, you can have painkilling tablets. Let your nurse know if you are in any pain so that they can adjust the painkillers for you. You may have mild discomfort for several weeks. Your doctor will give you a prescription for painkillers to take home with you if needed.

If you have keyhole / robotic surgery you may receive morphine-based painkillers for a day, but often men are able to manage with paracetamol and anti-inflammatory painkiller tablets.

Wound: It usually takes a few weeks for the wounds to heal. Sometimes they appear swollen and bruised but this will settle down with time. Healing on the inside of your body will take a bit longer.

It is important to keep the wounds clean and dry until healed.

Avoid heavy lifting and manual work for up to 8 weeks after the surgery. Your doctor or nurse will be able to advise you about this and also when you can return to driving.

Sluggish bowel: The anaesthetic during surgery may slow down your bowels. As a result, it may take a day or two before you can start eating and drinking normally again after open surgery. The risk of sluggish bowel is much less with keyhole or robotic surgery.

Infection and blood clots: A physiotherapist will show you breathing exercises to help prevent a chest infection. He or she will also show you how to cough without hurting yourself and how to move in the bed. You might find it helpful to hold a pillow or folded towel over your wound when you cough for the first few days.

Even when in bed, you should move your legs and do your deep breathing exercises at least once an hour. This will help to prevent blood clots. On the day after surgery, your nurses will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better.
Urinary catheter: The urinary tube will stay in place for between 1 and 3 weeks after your surgery. The urine you make will pass through the tube into a drainage bag. The catheter drainage bag will be worn inside your trousers and will be secured around your lower leg. Before you go home, your nurse will show you how to look after the drainage bag. It is important that the urine can drain easily from your bladder and into the drainage bag.

You might experience bladder spasms while the tube is in place. This often feels like a strong urge to pass urine, despite the tube being there. This is normal, but talk to your nurse if this happens to you a lot. It may happen when your bowels move. Your doctor can prescribe medication if this becomes a problem for you.

Tips & Hints – Catheters

- Try to drink plenty of fluids every day to reduce the risk of getting an infection: between 1.5 and 2 litres is often best.
- Avoid drinks with alcohol or caffeine in them.
- Wash your hands before and after handling the catheter. When washing the catheter entry tip, wash in a one-way direction away from your body.
- Speak with your nurse if you notice any leaking around the outside of the catheter or if you the notice that the catheter is not draining correctly.

Leaving hospital

If you have surgery, it’s best to plan as much as you can ahead of the discharge date. Ask to speak to a medical social worker about the community services that are available, especially if you live alone. Usually, the public health nurse in your area will visit you at home. If dressings are needed, make sure you have some supplies at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem. Talk to your specialist nurse, public health nurse or a pharmacist about getting a supply of incontinence pads. Make sure you have a supply at home before the urinary tube (catheter) is removed. See page 65 for more about pads.

Going home

If you have open surgery you may have stitches just under the skin. These don’t need to be removed as they are dissolvable. If your wound is closed with clips, these will need to be removed. This may be done before you leave hospital, or your practice nurse, public health nurse or GP might remove them when you go home. Contact your GP or the hospital as soon as possible if your wound becomes swollen, red or painful. This could be a sign of infection.

On the day you go home, you will be given a date to have your urinary tube (catheter) removed and often another appointment to see the surgeon. This is usually about 6 weeks after the operation. If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, nurse or hospital ward for advice.

Removing the urinary tube

You will need to go to the hospital or to your GP to have your urinary tube (catheter) removed. This takes just a few seconds. Most likely you will experience some leakage of urine once the tube is removed. This is normal and usually improves with time. Your nurse will give you an incontinence pad to wear, along with a small supply to take home. She or he can also give you information about how to get a supply of pads for yourself. It is important to keep doing pelvic floor exercises once your catheter has been removed to try and reduce urine leakage. If you need help with pelvic floor exercises, ask your nurse.

I expected it would take 4-6 weeks to recover but it actually took me 4 months to recover fully.
What are the side-effects of surgery?
The main side-effects of surgery are:
- Leakage of urine (urinary incontinence)
- Problems with erections (erectile dysfunction)

Talking to your doctor and nurse, or another man who has had surgery for prostate cancer, may help you to understand the impact of these side-effects on your daily life. Call our Cancer Nurseline on 1800 200 700 if you would like to be put in contact with a trained volunteer who has had treatment for prostate cancer.

Urinary incontinence: Urinary incontinence means you cannot control the flow of your urine. Almost all men will have trouble with leakage of urine in the first weeks and often months after surgery. The risk of urinary leakage is the same for open, keyhole and robotic surgery. Talk to your surgeon or nurse about the risk of urinary incontinence before you consent to surgery.

You will probably need to wear an incontinence pad for a time to collect the leaked urine. As time goes on, you are likely to regain control of your urine flow and you won’t need to wear pads any more. Or perhaps you will only need one pad a day or just when you exercise. A small number of men do not regain complete control over their urine flow and need to continue wearing pads. Tell your surgeon if this happens.

Erectile dysfunction (impotence): Surgery to your prostate gland often leads to problems having an erection. This is called erectile dysfunction (ED) or impotence. It is caused by damage to blood vessels or nerves near your prostate. Even a small amount of damage can lead to erections failing, especially if you are older and have high blood pressure or diabetes. Nerve-sparing surgery can improve your chance of getting your erections back after surgery. See page 51 for more details.

If you had problems with erectile dysfunction before surgery, you are more likely to have these problems after surgery too. Up to 7 in 10 men have erectile dysfunction after a radical prostatectomy.

At first you might find it difficult to get an erection, and it may well not be strong enough for sex. It can take at least a year after surgery to find out if the impotence will get better or not. You may need medication or other treatments to help you get an erection.

If you have problems with erections, talk to your surgeon when you go for check-ups, or talk to your GP or nurse. There’s more information on sex and erectile dysfunction on our website www.cancer.ie. You can speak to cancer nurse in confidence by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre. You can also email the nurses at cancernurseline@irishcancer.ie

Early treatment for erectile dysfunction
Taking medication or using a vacuum pump for erectile dysfunction soon after surgery can improve your chance of having erections again. Even if you’re not interested in sex, taking the tablets or using a vacuum pump at an early stage may improve your chances of having erections if you want to have sex again in the future. Do discuss this with your surgeon, nurse or your GP.

‘Dry orgasm’: After prostate surgery, an orgasm will not cause an ejaculation of semen. This is known as a ‘dry orgasm’. Many men describe the sensation of orgasm as different to their orgasm before surgery. A few men describe it as lasting longer, others describe some pain after orgasm in the early days, or some simply describe it as different. A dry orgasm means that you cannot father a child in the future. Tell your surgeon if you think you might wish to father children after your surgery, as it may be possible to store your sperm before treatment starts. See page 70 for more on infertility.

How to cope with urinary incontinence
For tips on coping with urinary incontinence and information on treatments available, see page 63.
Shortening of your penis: Up to a year after surgery you may notice your penis has shortened. Some treatments for erectile dysfunction that encourage blood flow into your penis, such as tablets or a vacuum pump, may help to prevent it. See pages 66-67 for more information.

Advantages of prostate surgery
- Surgery will completely remove the cancer if it is only in the prostate gland.
- The prostate can be removed and be fully analysed and staged in the laboratory.
- The success of the treatment can be easily assessed by PSA-testing.
- If the PSA were to rise after surgery you would still be able to get other treatments like radiotherapy or hormone treatment.

Disadvantages of prostate surgery
- It involves a general anaesthetic and the usual risks you would expect with surgery, like the risk of bleeding, infection and blood clots. It involves a short stay in hospital for a few days.
- You may get side-effects afterwards like problems with erections and urinary incontinence.
- You will not be able to father children after the surgery, as the prostate, which normally makes some of the fluid needed for semen to be made, has been removed.
- Recovery takes around 6 weeks.

To sum up
- The aim of surgery is to remove your entire prostate gland and the cancer within it. The operation is called a radical prostatectomy.
- There are different types of surgery. They include open prostatectomy, keyhole surgery and robotic surgery.
- A nerve-sparing prostatectomy may be done to protect the nerves next to your prostate that are responsible for erections.
- A urinary tube (catheter) will stay in place for between 1 and 3 weeks after your surgery.
- Many men have trouble with control of urine flow after a radical prostatectomy. Usually this improves over the weeks and months after the operation.
- Problems with urinary incontinence and erections are common side-effects of surgery for prostate cancer. These problems can often be improved with treatment.

Watchful waiting
Watchful waiting can be a treatment option if you have health problems that make other treatments unsuitable. You will have regular tests to check your PSA levels and sometimes digital rectal examinations done by your hospital or GP. You will also be monitored for new symptoms such as difficulty passing urine or bone pain. You won’t need regular biopsies unless your cancer starts to grow. If your PSA level rises or if you develop symptoms you will be referred back to your cancer specialist. If there are no signs of the cancer growing it’s safe to continue with watchful waiting.
Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching prostate cancer. Your doctor can advise you about this.

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

More information

It’s best to talk to your doctor if you’re interested in taking part in a clinical trial. If you want more information, you can read our factsheet Cancer and Clinical Trials.

You can get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre. Or go to our website, www.cancer.ie

You can see a list of current cancer trials at www.cancertrials.ie
Fatigue

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer.

Fatigue when you have cancer can be caused by many things, including the cancer itself, tests and treatments for cancer, not eating well, low levels of red blood cells (due to the cancer or its treatment), dealing with difficult emotions and feeling anxious or depressed, not sleeping well or symptoms like pain, breathlessness or fluid retention.

Fatigue can continue for a number of weeks or months after treatment. It’s important to tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count a transfusion can make you feel better. If you are not eating well a dietitian may be able to give you some advice to help you.

Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat a balanced diet and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

A helpful booklet called Coping with Fatigue is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.

Urinary problems

Different treatments for prostate cancer can cause different urinary symptoms. You can read more about each treatment’s possible side-effects in the treatment sections on pages 32-59.

Urinary symptoms normally improve with time, but if they carry on for a long time, your doctor may recommend surgery or other treatments.

Some of the symptoms you might experience include:

- Leaking urine (urinary incontinence)
- A slow flow of urine / Difficulty emptying your bladder fully
- Passing urine frequently (more than 8 times a day).
- A sudden urge to go to the toilet quickly (urgency)
- Blood in the urine

Urinary symptoms are most common after surgery for prostate cancer.

Leaking urine

Leaking urine is a common side-effect of prostate cancer surgery. You may leak just a few drops of urine when you cough, laugh or exercise or it can be a constant drip or trickle throughout the day. Or you may leak some urine before you get to the toilet or after you have been.

If you need advice about coping with leakage, ask your doctor, public health nurse or see if there’s a continence advisor at your local HSE health centre. There are things that can help, so don’t suffer in silence. See our hints and tips on page 64 for advice.

Carry the card

The Irish Cancer Society have a card that you can show at shops and other public places to get urgent access to a toilet. Get one from a Daffodil Centre or by calling our Cancer Nurseline on 1800 200 700.
A slow flow of urine / Difficulty emptying your bladder fully
A slow flow of urine may be caused by a narrowing of your urethra (water pipe) after surgery or radiotherapy. If you have a slow flow of urine let your urologist know, so they can find the cause and see if you need treatment. If you have a slow flow of urine your doctor may give you tablets called alpha blockers to help. These can help to relax the muscle within the prostate and to reduce the narrowing of the water tube that runs through the centre of the prostate. Or you may need a short procedure to widen the tube to help you to pee more easily again.

Tips & Hints – Managing urinary problems
Your doctor can help you to manage urinary problems, so always tell him or her if you have any symptoms. You could also try the following:

- Try cutting down on food and drinks with caffeine, like cola, tea, green tea, coffee and dark chocolate, as they may irritate your bladder.
- Try drinking less alcohol. Alcohol can increase the amount of urine you produce, making it more likely you’ll have to get up during the night.
- Drink plenty of fluids every day – about 2 litres a day (average 6-8 cups). Not drinking enough will make your urine more acidic and this may irritate more.
- If you find it hard to get to the toilet in time, make sure you can reach it easily and that your clothing can be easily undone.
- Try to eat plenty of fibre to avoid constipation. Constipation can put pressure on your bladder and make urinary problems worse.
- Exercise regularly, as it will help your bowels to work well. Your doctor can advise you about suitable exercises for you.
- Keep the area clean and dry to avoid skin irritation and to stay fresh. Use a mild soap and gently pat the area dry.
- Go to the toilet at regular intervals.
- Wear trousers with an elasticated waist, or use braces rather than a belt. This makes it easier when you want to go to the toilet quickly.
- Try having a rest in the afternoon. It may help the muscles around your bladder to tighten up and work better for you.
- Plan ahead – keep a bag with wipes and pads with you, and make sure you know where the public toilets are if you’re going out.
- Bed protectors are available if you’re worried about leaking during the night.

Incontinence pads
You may need to wear pads to absorb leaks for some weeks or months. You can get pads from your local pharmacy or online. If you have a medical card your public health nurse may be able to get the pads for you.

Try a few different sizes and absorbencies until you get the right pad to suit you. Using a pad that absorbs more than you need can make your skin sore, so pick a smaller size as your leakage reduces. Wear supportive underpants or special net pants to help keep pads in place.

Pelvic floor exercises
Pelvic floor exercises can help to strengthen the muscles around your bladder and in the pelvic floor and may improve your bladder control. Get advice from your hospital team or a local HSE continence advisor. There are instructions on how to do the exercises on our website, www.cancer.ie

The ‘Knack’
‘The knack’ is a technique to help to reduce leakage. The knack involves squeezing your pelvic floor muscles before you cough, sneeze or laugh or before or during other activities that can make leakage worse. Go to www.cancer.ie for more information.

Cancer Nurseline Freephone 1800 200 700
Sexual problems

It is natural for you to be concerned about your sex life. Treatment can affect you physically and mentally when it comes to sex. Fatigue, loss of libido (sex drive), changes to the way you ejaculate, urinary incontinence and erectile dysfunction (ED) can all affect your sex life. Some men with prostate cancer feel that changes to their sex lives and their relationships are some of the biggest issues they face.

For more details on sexual side-effects see the individual treatment sections:
- Sex after brachytherapy – page 39
- Sex after radiotherapy – page 45
- Sex after surgery – page 56
- Sex and hormone therapy – page 49

Treatment for sexual problems

Not every man wants treatment for erectile problems. Some men accept the changes in their body and don’t feel the need to get treatment. For other men, finding a way to treat their erectile dysfunction is very important. There is no right or wrong way to react – just the way that feels right for you.

The treatment options for erectile dysfunction include:

Tablets: Sildenafil (Viagra®), tadalafil (Cialis®) and vardenafil (Levitra®) are all examples of tablets that can help men to get erections. You need to be interested in sex and have sexual stimulation for them to work.

Tablets are often used as a first treatment for erectile dysfunction after prostate cancer. However, it is quite common for them not to work on their own. Many men go on to use another treatment with more success.

Urethral pellets: A urethral pellet can be put into the opening or ‘eye’ of your penis. Then the pellet is massaged into the penis to help it melt. Standing or walking around can help your erection develop better.

Penile injections: The idea of injections is that they cause the penis to fill with blood. You should get an erection within about 15 minutes. The erection lasts from 30 minutes to 2 hours.

The first dose is given by your doctor in the hospital so that they can see how well you respond and decide the best dose for you. Then you or your partner will be taught how to give the injection at home. The injection does not hurt, as the needle is very fine. You should not inject more than 2 or 3 times a week.

Vacuum pump: A plastic tube is placed over the penis and a pump is used to create a vacuum. This causes blood to flow into your penis, creating an erection. A rubber ring is then put around the base of your penis to hold the blood in the penis and keep the erection for up to 30 minutes.

Some men prefer the pump because it avoids the use of drugs. Another advantage is that the cost of the pump is a once-off payment. Although most men find the vacuum pump effective, some men find it awkward to use. It can take some practice to get the technique just right for you. You can use the pump as often as you like. It can also be used together with tablets or injections.

You may be advised to use to pump to encourage blood flow to your penis after surgery or radiation treatments, even if you are not ready to have sex.

There is more information on using a vacuum pump on our website, www.cancer.ie

Penile implants (surgery): Penile implants can be an option for men who have had erectile dysfunction for at least a year and have tried all other methods. The implant consists of a pair of tubes attached to a reservoir and a pump. This is placed inside your body during an operation. By pressing on the pump, the fluid in the reservoir moves into the tubes to form an erection or rigid penis. Most men and their partners are very satisfied with these devices. Side-effects include infection and pain. Rarely, the device stops working properly.
There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise you if you can have sex during radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery. Some people fear that cancer can be passed on to a partner during sex. This isn’t true.

Help with your emotions

If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

Changes to your sex life can have an effect on your mood. For example, you may feel angry or frustrated by these changes. If you are finding it hard to cope, talk to your GP, hospital doctor or nurse. Getting support or advice can help to stop these feelings building up too much. You may find it useful to get in touch with a cancer support centre. Some centres offer free one-to-one counselling sessions to help you to deal with your feelings. For more information on cancer support centres and counselling, call the Cancer Nurseline on 1800 200 700 or visit www.cancer.ie.

See page 74 for more about managing your feelings and getting emotional support.

Asking for advice

If you have any questions about how treatment may affect your sex life, ask your doctor or nurse. Don’t be embarrassed – Your doctor and nurse are well used to talking about these matters and will give you advice. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie.
**Contraception**
If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Many specialists recommend that you wait for up 2 years after treatment before trying to start a family or to have more children. This gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor’s advice about contraception or if you are thinking about having children after treatment.

**Will treatment affect my fertility?**
Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your sperm before starting treatment. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where sperm can be frozen for later use.

Dealing with infertility may not be easy, depending on your age and if you have already had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

**What follow-up do I need?**
After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up will involve PSA tests (see page 9) and maybe a digital rectal exam (DRE). At first you will see your consultant every 3 months but these check-ups will become less frequent. You may have follow-up appointments to check your PSA for many years. Some men have PSA tests at the hospital or you may have them at your local GP surgery.

**What is PSA bounce?**
If treatment has been successful you would expect the PSA level to drop. Sometimes your PSA may rise again after radiation treatment, as some prostate cells may still produce PSA. Sometimes the PSA level may rise and then fall again one to two years after treatment. This is called a PSA bounce. It is not necessarily a sign that the cancer has come back. The PSA should drop to its lowest level after 18 months to 2 years after radiotherapy. This is often called the PSA nadir.

**Getting the most from your appointment**
Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor, so that you don’t forget. If you are between check-ups and have a symptom or problem that is worrying you, tell your doctor or nurse. Make an appointment to see him or her as soon as possible.

**Staying healthy after treatment**
Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle is important as it can help you to:
- Feel better
- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength
- Not smoking
- Protecting yourself from the sun

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back. A healthy lifestyle includes:
- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website [www.cancer.ie](http://www.cancer.ie) for tips and publications on healthy living.
Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

**Complementary therapies:** Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of these therapies are yoga, meditation, aromatherapy and massage.

**Standard treatment:** Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

**Alternative therapies:** Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may harm your health.

If you decide to have complementary or alternative treatments...

Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. Others can interfere with standard treatment or cause serious side-effects.

More information

To find out more about the different complementary and alternative therapies read our booklet Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients. To get a copy or for more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie

Email: cancernurseline@irishcancer.ie
How can I cope with my feelings?

People react in different ways when they find out they have cancer. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

- Shock and disbelief
- Sorrow and sadness
- Fear and uncertainty
- Denial
- Loss of control
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it’s important to get help. It is not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

‘Men are not always comfortable talking about their feelings.’

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Free counselling is available at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at [www.cancer.ie](http://www.cancer.ie).

Ways to get emotional support:

*Find out about cancer support services in your area.* There are lots of local cancer support services that provide a range of helpful services such as one-to-one counselling, complementary therapies, exercise programmes, practical advice and support. See page 88 for more about cancer support services.

*Ask about psycho-oncology services at the hospital.* Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

*Join a support or educational group.* Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

*Get one-to-one support.* The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

*Get online support.* There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit [www.cancer.ie/community](http://www.cancer.ie/community) to join the Irish Cancer Society online community.

*Talk things through.* It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

*Seek spiritual support.* For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

*If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.*
Learning to cope
Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, most people are able to adjust to life during treatment.

\[\text{It's OK to be gentle with yourself. It can be hard to sit back if you've been active all your life, but give yourself that time}\]

How can I help myself?
Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and wellbeing, making it easier to deal with cancer.

Use your support network. Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don’t be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends. Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

Gather information about your cancer and treatment. Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Get some exercise. Exercising is a great way to boost your mood and sense of well-being. Exercise can also improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

Try relaxation and stress management techniques. Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Try complementary therapies. Complementary therapies may help you to cope with the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 72 for more information on complementary therapies.

Accept change in your life. Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs. Sometimes people feel they have to be brave or positive all the time, but it is normal to have bad days. Get help if you are finding it hard to cope.

Keep busy. Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

Try to cope day by day. Don’t think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Express yourself. Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.
Further information and support
If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Advice for carers
Caring for someone with cancer
Caring for someone who has had treatment for cancer can be difficult at times. Coping with both the practical and emotional issues of treatment can be hard. Here are some things that can help to make life a little easier:

- **Learn about cancer:** Learn more about prostate cancer, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend.
- **Plan as much as you can ahead of the discharge date:** Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.
- **Encourage your relative or friend:** At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

You and your family
Every family deals with cancer in its own way. You may feel that you don’t want your illness to upset family life, feel guilty that you can’t join in as much as before, or that you’re letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Who Can Ever Understand?* can help to you find ways to talk about your cancer and to ask for the help and support you need.

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren’t sure what to say to them.

You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.

How can my family and friends help?
Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice, some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.

Positive emotions
A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what’s important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

Email: cancernurseline@irishcancer.ie
Understanding prostate cancer

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet Lost for Words – How to talk to someone with cancer. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie

Looking after yourself

- **Share worries:** You may feel tired with all the worry and extra work. It can also be difficult to adapt to a new way of life. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can.

- **If you find it difficult to cope, get help:** Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

- **Look after your own health:** See your GP sooner rather than later if you have any health concerns of your own.

- **Find carers support organisations or local cancer support centres:** Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

Support for you

Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information. You could also ask for a copy of our booklet, Caring for Someone with Cancer, or download it from our website www.cancer.ie

Life after cancer

Being told your treatment has been successful is wonderful news. But it can take some time to adjust to life after cancer treatment. It isn’t unusual to feel quite low and lost after your treatment has ended, especially during the first few months. Feelings you may have include:

- **Fear of cancer coming back** and worrying about every small symptom

- **Loneliness** without the company and support of your medical team and fellow patients

- **Stress** at having to deal with concerns such as your finances, going back to work and family issues that may have been on hold during your treatment

- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready

- **Anxiety and self-doubt** about sexual and romantic relationships

- **Anger** at what has happened and the effect on you and your loved ones

- **Depression or sadness**

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie/coping/life-after-cancertreatment

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 75 for other ways to get support.
Support resources

Coping with the financial impact of cancer 84
Irish Cancer Society services 86
Local cancer support services 88
Helpful books 89
What does that word mean? 90
Questions to ask your doctor 91
Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can’t work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:
- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication. If you are over 70 years old, you can get a free GP visit card.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It’s important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer’s Allowance, Carer’s Benefit, Carer’s Leave.

If you want more information on benefits and allowances, contact:
- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It’s also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice.

The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 87 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Cancer Nurseline Freephone 1800 200 700
More information
For more information go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:
- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

Irish Cancer Society services
Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- **Cancer Nurseline**
- **Daffodil Centres**
- **Survivor Support**
- **Support in your area**
- **Patient travel and financial support services**
- **Night nursing**
- **Publications and website information**

- **Our Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- **Our Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

- **Our Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area**. We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 88 for more information.

- **Patient travel and financial support services**. We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing**. We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

- **Our publications and website information**. We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.
Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free, one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society’s Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig-fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what’s available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at [http://www.cancer.ie/support/support-in-your-area/directory](http://www.cancer.ie/support/support-in-your-area/directory)

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: [www.cancer.ie](http://www.cancer.ie).

You may find the following helpful:

**Treatment and side-effects**
- Understanding Chemotherapy
- Understanding Radiotherapy
- Understanding Cancer and Complementary Therapies
- Diet and Cancer
- Coping with Fatigue

**Coping and emotions**
- Understanding the Emotional Effects of Cancer
- Lost for Words: How to Talk to Someone with Cancer
- Who Can Ever Understand? Taking About Your Cancer
- Caring for Someone with Cancer
- Talking to Children about Cancer: A Guide for Parents
- A Time to Care: Caring for Someone Seriously Ill at Home
**Questions to ask your doctor**

Here is a list of questions that you may wish to ask. Never be shy about asking questions. It is always better to ask than to worry.

- **What tests do I need?**
  - How long will I have to wait before the tests?
  - Do I need treatment straight away? If not, how will you know when I should have treatment?
- If I need treatment, what are my treatment choices?
  - How successful is this treatment for my cancer?
- If my treatment is not successful, can I still have other treatments?
  - Do some treatments have more side-effects than others?
- Will I need hormone therapy and radiotherapy? If yes, for how long?
  - Are the side-effects of treatment short or long term?
- Will I have problems with urinary incontinence after my treatment?
  - Will treatment affect my fertility? Will I develop erectile dysfunction?
- Why is follow-up so important? Why do I need regular blood tests?

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**What does that word mean?**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign</td>
<td>Not cancer. A tumour that does not spread.</td>
</tr>
<tr>
<td>Biopsy</td>
<td>Removing a small amount of tissue from your body to find out if cancer cells are present.</td>
</tr>
<tr>
<td>Brachytherapy</td>
<td>A type of internal radiotherapy. Solid radioactive seeds are placed inside your body on or near your tumour.</td>
</tr>
<tr>
<td>Catheter</td>
<td>A long thin flexible tube that is passed into your bladder. It drains urine into a bag.</td>
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<tr>
<td>Enema</td>
<td>A fluid solution inserted in through your back passage which causes you to clear your bowels.</td>
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<tr>
<td>Erectile dysfunction</td>
<td>When you cannot get or keep an erection.</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Ongoing tiredness often not helped by rest.</td>
</tr>
<tr>
<td>Fiducials</td>
<td>Small gold objects that are implanted in your prostate to mark where the radiation will be aimed during each treatment.</td>
</tr>
<tr>
<td>Grading</td>
<td>Checking how normal or abnormal the prostate cells look under a microscope.</td>
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<tr>
<td>Incontinence (urinary)</td>
<td>When you cannot control the leakage of urine from your body.</td>
</tr>
<tr>
<td>Metastasis</td>
<td>When cancer spreads from one part of your body to another.</td>
</tr>
<tr>
<td>Prognosis</td>
<td>The expected outcome of a disease.</td>
</tr>
<tr>
<td>PSA</td>
<td>Prostate specific antigen. This is a protein made by your prostate gland. It can be measured in your bloodstream.</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>A doctor who specialises in treating cancer patients using radiotherapy.</td>
</tr>
<tr>
<td>Radical prostatectomy</td>
<td>An operation that removes your entire prostate gland and seminal vesicles.</td>
</tr>
<tr>
<td>Rectum</td>
<td>The lower part of your bowel. Also called your back passage.</td>
</tr>
<tr>
<td>Staging</td>
<td>Tests that measure the size and extent of cancer.</td>
</tr>
<tr>
<td>Urologist</td>
<td>A surgeon who specialises in treating prostate, kidney and bladder disease.</td>
</tr>
</tbody>
</table>
Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer
Reaching out directly to people with cancer is one of the most rewarding ways to help:
- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences
Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:
- Share your cancer story
- Tell people about our services
- Describe what it’s like to organise or take part in a fundraising event

Raise money
All our services are funded by the public’s generosity:
- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?
We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

More information and support
If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.